DOH Autism Pilot Programs Fact Sheet

Updated June 2014

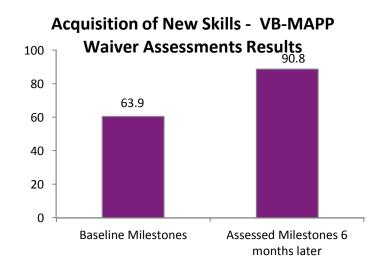


With the passage of HB272 in the 2012 Legislative Session, a two-year autism services pilot was created. The pilot was

divided into three sub-pilot programs. Two of the pilots were based in the Utah Department of Health: The Medicaid Autism Waiver (Waiver) and the Autism Treatment Account (ATA). The pilot programs serve children with autism spectrum disorders, ages 2 through 6 years old.



The Waiver received an appropriation for \$4.5 million in general fund, with an accompanying \$10.5 million in federal funds. The ATA received an appropriation for \$1 million in general fund, with \$750,000 in private donations.



Treatment

Applied Behavior Analysis (ABA) is the primary service offered in the pilots. ABA involves teaching skills that facilitate development by breaking the skills into smaller parts and working on one sub-skill at a time until mastery is achieved. A key component to the success of the ABA model is family participation.

Enrollment and Costs

The Waiver provided services to 317 children at an average cost of \$23,300 per child per year. The ATA provided services to 35 children per year at an average cost of \$29,500 per child per year (49 different children participated).

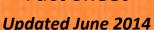
Outcomes and Effectiveness

Participating children were assessed before services were initiated and again six months after services began. The outcomes for children receiving services were positive and demonstrated that treatments resulted in the acquisition of new skills.

Ongoing Program

The passage of HB88 during the 2014 Legislative Session converted the Medicaid Autism Waiver pilot program into a permanently funded ongoing program. The program received just over \$1.8 million in ongoing general funds and \$4.2 million in ongoing federal funds to continue operations. This level of funding will allow an average of 260 children to be enrolled in the program. The Department will continue to accept applications during open enrollment periods and distribute the available slots proportionally throughout the state. The ATA did not receive any new appropriations and will provide services until the funding is exhausted.

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One Family's Experience - Excerpts from a letter written by a parent of a child enrolled in the Medicaid Autism Waiver. Used with permission of the family. (Note – this family lives in a rural area in Southeastern Utah).

To Whom it May Concern,

My son Owen was diagnosed with Autistic Disorder and Communication Disorder on October 17, 2012. At that time, he was classified as having significant language delays because he had no meaningful language. At the age of 27 months, Owen did not even have one word that he would use. He appeared to have no understanding or recognition of any verbal language. He gave no response to his name, or physical contact. Owen made little or no eye contact and avoided engagement of any kind. He would walk away, cover his ears, or just shut his eyes to try and escape. My son never shared in mutual enjoyment with my husband or me.



We were tools he would use as a method of getting the things that he needed or wanted. I started to notice that he would become physically tense and visibly anxious or agitated when he was around other children. He would hold his ears and rock, pace in circles, or other self-stimulating behaviors due to the amount of stimuli that being around children provides. He had no self-regulation, staying awake for twenty or more hours at a time. He would avoid solid foods for weeks at a time. My husband and I were desperate for help and guidance, especially in rural Utah where there are no Autism Services available outside of the public school system. The pilot program for Autism Spectrum Disorders Services came at the perfect time.

After my son was approved for the Medicaid Autism Waiver we selected a provider and began Applied Behavior Analysis (ABA). Within the first week of services my son was making requests for rewarding items using a Picture Exchange type of system. He would even differentiate and avoid pictures of the "undesirable" items that he was given as options. By the second week, he was 100% accurate using this system to request desired items. On June 10, 2013 Owen made his first verbal request, saying "iPad," after he was asked "what do you want?" Soon after, I was rewarded, by hearing him call me "Mama-Ma" for the first time. My son now has 95-100% accuracy responding to his name, and the request to sit down. When given the request to come to us, he is 80% accurate. After only 4 months of ABA, my child would parrot any word, sound, or expression that he is asked to, started learning to label people and things, and making verbal requests. Currently, Owen is verbally spelling his name, tracing and trying to write his name, counting to 10, and even requesting "mama, help." This is the same child with 'significant language delays.' But the most important progress is that now my son enjoys hugging, kissing, and playing with his father and me. He initiates activities that we share together, and he runs to greet us when we get home. He even acknowledges people when they arrive and waves goodbye and says "See ya later," to visitors. Owen will now approach adults and children to give them "high-five" as a way of initiation. I recently recorded a video clip of my son that I watch over and over. In the video he uses a pair of scissors to cut a strip of paper and he shouts out "I DID IT!" with so much joy and excitement. It is the first time in three years that his big personality finally shines through, and he actually had his own words to express himself. For the first time in his life, Owen has language enough to tell me that "He did it!" And he will do it. Owen has had a taste of success and he has enjoyed himself so much, that he will only improve faster, and work harder.

We still have a long ways to go to help my son understand the world around him. But the progress that he has made in just six months is astounding. According to his Speech Pathologist and Occupational Therapist, "he is a completely different kid." I look forward to the progress that my son and my family will make during the duration of this program. The education that my family is receiving with ABA is helping Owen to develop and become a contributing member of society that will not be dependent on future government funding. Thank you for this wonderful opportunity, for your time, your support, and the work that you all do. Please know that you are truly appreciated for the difference that you are making in individual lives and the lives of families that love those individuals.